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Factors associated with increased felt stigma among individuals with epilepsy

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ABSTRACT

Purpose: The aim of the study is to determine whether certain demographic, clinical, and psychosocial traits are associated with higher levels of felt stigma among persons with epilepsy (PWE) patients followed at a level 4 epilepsy center.

Methods: We performed a direct survey of 182 consenting patients that included the Epilepsy Stigma Scale.

Results: On univariate analysis, higher levels of perceived stigma were associated with age, marital status, race, driving, work status, seizure etiology, Quality of Life in Epilepsy-10 (QOLIE-10) scores, and health literacy. Among coping reactions, the use of denial, behavioral disengagement and venting were also associated with higher degrees of felt stigma.

Using multiple linear regression, being single, poorer QOLIE-10 scores, difficulties understanding written information, and the use of behavioral disengagement were independently associated with poorer scores on the Epilepsy Stigma Scale.

Conclusion: Our study paints a compelling profile of a PWE who has greater perceived stigma. Programs that increase the level of social support, improve health literacy, and enhance quality of life may also help decrease the amount of felt stigma among PWE.

1. Introduction

The eminent sociologist Erving Goffman once defined stigma as a "...phenomenon whereby an individual with an attribute which is deeply discredited by his/her society is rejected as a result of the attribute. Stigma is a process by which the reaction of others spoil normal identity." [1]. A more recent definition of stigma is "... a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem." [2].

The fear of societal stigma remains one of the most important factors that lead to psychological suffering among people with epilepsy (PWE). Fisher and colleagues [3] showed that more than half of PWE experienced fear, depression, or anger as their initial reaction to the diagnosis of epilepsy and a quarter of them expressed serious concerns about social stigma and the fear of others' reactions, often resulting in shame and loneliness. Another cross-cultural European study conducted in 1999 showed that more than half of PWE reported feeling stigmatized [4]. Stigma can be categorized into "enacted stigma" where actual discrimination takes place against PWE on the basis of their social unacceptability, and "felt" stigma which refers to the shame associated with having epilepsy and the fear of experiencing enacted stigma [5].

It behooves clinicians who manage PWE to understand the importance of stigma on overall wellness and the role it plays in impacting a patient's quality of life. Unfortunately, the impact of stigma on the lives of PWE is often underestimated by healthcare workers even though stigma affects quality of life even more than seizure frequency or the adverse effects of antiepileptic drugs (AEDs) [6–10].

In particular, an important question that remains unanswered is whether there are certain demographic, clinical, or psychosocial variables that are associated with enhanced felt stigma among individuals with epilepsy. More importantly, is there a certain psychosocial profile that is correlated with higher levels of perceived stigma? Knowing this would help identify those individuals who are having an especially difficult time coping with their condition. These PWE may benefit from added support and encouragement.

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In this study, we perform a direct survey of PWE who are followed at a Level 4 Comprehensive Epilepsy Program. The aim of the study is to determine those variables that are associated with a high degree of felt stigma and using multivariable analysis, to identify those that are independently significant. We opted to examine a large number of potential predictor variables in this study in order to create a comprehensive profile of a PWE who perceives a high level of felt stigma. In addition, new variables that until now have not yet or have only been rarely addressed in this context, such as health literacy, were included in this study.

2. Methods

The Institutional Review Board of the University of Florida Health Sciences

Center/Jacksonville (UFHSCJ) approved this study.

This study is an extension of a previous work that was detailed in an earlier publication [11]. We performed a direct survey on adult epilepsy patients who were being followed at the UFHSCJ-Comprehensive Epilepsy Program (CEP) outpatient clinics from February to June 2014. These patients had a diagnosis of localization-related epilepsy and had no history of non-epileptic events. They were their own primary caregivers and could complete the survey without assistance.

The UFHSCJ-CEP is a level 4 epilepsy center located in downtown Jacksonville, Florida and is a major referral center in the region. Around 42% of patients seen at the UFHSCJ-CEP are males, 58% are Caucasians and 31% are African-Americans. A significant portion of patients seen at the UFHSCJ-CEP come from the indigent population and 40% of patients are either uninsured, part of the city's indigent care program or recipients of Medicaid/Medicaid HMO programs. Around 5% of patients have undergone epilepsy surgery and/or vagus nerve stimulator implantation.

A copy of the survey can be found in the supplementary section (Supplementary Material 1).

We obtained the following information:

Demographic information: age, gender, marital status, ethnicity (Hispanic versus non-Hispanic), race, educational attainment, annual household income, whether they drive, whether they receive disability benefits, current employment status.

Disease-related information: age at seizure onset, seizure duration, seizure frequency, whether they experience convulsions, whether they experience seizures while awake, seizure etiology, number of AEDs (antiepileptic drugs) they are currently taking, severity of side effects from their current AED regimen.

Psychosocial Data: Quality of Life in Epilepsy-10 (QOLIE-10) [12], Beliefs About Medicines Questionnaire-Specific (BMQ-S) [13], Screening Questions for Health Literacy [14], Brief Coping with Problems Experienced (Brief-COPE) Inventory [15], and the Epilepsy Stigma Scale (ESS) [16].

The QOLIE-10 is a shorter form that is derived from the QOLIE-89. It covers epilepsy-targeted and general aspects of mental and physical health as well as social and role functioning. Health related quality-of-life issues in patients with epilepsy are categorized into three distinct areas: (a) medication effects, (b) mental health, and (c) role functioning and seizure worry. Test–retest data shows significant Pearson's correlations for individual items (range, $r = 0.48–0.81$). Scores range from 10 to 50 with higher scores indicating poorer quality of life [12].

The BMQ-S assesses commonly held beliefs about medicines. Subjects are given 10 statements that reflect different attitudes toward the use of prescribed medications with responses answered across a 5-point Likert scale. The items of the BMQ-S reflect both patient concerns about potential adverse effects of medications as well as beliefs in the necessity of their prescribed medications. Responses have been tested in patients across various disease states, and the internal consistency of the BMQ-S ranges from 0.55 to 0.86 (Cronbach alpha) [13]. In this study, we obtained a BMQ-S Necessity minus Concerns score with higher scores indicating strong patient beliefs in the importance of their seizure medications.

We included three screening questions for health literacy taken from the Short Test of Functional Health Literacy in Adults (STOHFLA) ("How often do you have someone help you read hospital materials?", "How confident are you filling out medical forms by yourself?", and "How often do you have problems learning about your medical condition because of difficulty understanding written information?") [14]. When compared with overall STOHFLA scores, Chew and colleagues [17] showed that responses to each of these three questions correlate well with detection of inadequate health literacy.

The Brief-COPE is used to assess an individual's coping strategy. It is a 28-item self-reported questionnaire taken from the original COPE measuring 14 distinct subscales of coping reactions (2 questions each): self-distraction, active coping, denial, substance abuse, emotional support, instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. Each item is scored from 1 (I haven't been doing this at all) to 4 (I've been doing this a lot) and we obtained the total score of the 2 questions that reflect each coping mechanism. Thus, there is a minimum score of 2 and a maximum score of 8 for every coping reaction. Test–retest reliability for the various coping strategies ranges from 0.46 to 0.86 [15]. In this study, COPE questions were structured to assess *dispositional coping* which reflects stable coping tendencies, as opposed to *situational coping* which reflect those strategies employed for particular situations which may differ across various situations [18].

We assessed perceived stigma using the Epilepsy Stigma Scale (ESS). This scale was adopted by DiIorio and colleagues [16] from the Parent Stigma Scale earlier developed by Austin and colleagues [19]. It is a 10-item scale that assesses the degree to which a person believes that epilepsy is perceived as negative and interferes with one's relationships with others. Items are rated on a 7-point scale with higher scores indicating a higher degree of felt stigma. The alpha coefficient for responses to the ESS shows high internal consistency (0.91) [18].

3. Statistical analysis

Statistical analysis was performed with SPSS 15.0 at a 5% level of significance using a 2-tailed test. Interval variables were transformed, if necessary to satisfy the assumptions of parametric analysis.

We performed univariate analysis to determine the association between scores on the Epilepsy Stigma Scale and the various demographic, clinical, and psychosocial variables. Interval data and near-interval data were analyzed using Pearson correlation and Spearman's rho respectively. Categorical data was evaluated using analysis of variance with pair-wise comparison performed on significant variables using Bonferroni correction. Ordinal data was analyzed using Kruskal–Wallis.

Multiple linear regression was performed on significant variables identified by univariate analysis ($p < 0.5$) to determine those that were independently associated with higher scores on the Epilepsy Stigma Scale.

4. Results

Over 95% of patients who met the study criteria agreed to participate in the study. One hundred and eighty two continuous consenting patients completed the survey and were included in this study. Table 1 details the characteristics of our study

Table 1
Descriptive data[a].

Number of respondents, *n*	182
A. Demographic variables	
Age in years, mean (SD)	42.8 (14.2)
Males, *n* (%)	56 (30.8)
Marital status	
Single, *n* (%)	89 (48.9)
Married, *n* (%)	68 (37.8)
Divorced, *n* (%)	18 (9.9)
Widowed, *n* (%)	7 (3.7)
Hispanics, *n* (%)	5 (2.9)
Race	
Caucasian, *n* (%)	107 (56.6)
African-American, non-Hispanic, *n* (%)	65 (34.4)
Others, *n* (%)	17 (9)
Highest Educational Level	
Less than high school, *n* (%)	42 (22.2)
High school, no college, *n* (%)	71 (37.6)
Some college/associates degree, *n* (%)	51 (27)
Bachelor's/technical degree and higher, *n* (%)	25 (13.2)
Annual household income	
Less than $10,000, *n* (%)	85 (55.3)
Between $10,000 and $50,000, *n* (%)	71 (39.2)
Between $50,000 and $100,000, *n* (%)	20 (11)
More than $100,000, *n* (%)	5 (2.8)
Drives a motor vehicle, *n* (%)	44 (24.3)
Receives disability benefits, *n* (%)	106 (58.6)
Work status	
Works full-time, *n* (%)	18 (10.1)
Works part-time, *n* (%)	9 (5.1)
Unemployed, *n* (%)	151 (84.8)
B. Clinical variables	
Age of seizure onset in years, mean (SD)	22 (16.8)
Seizure duration in years, mean (SD)	20.6 (16.8)
Seizure frequency	
Daily, *n* (%)	8 (4.5)
Less than daily but more than once a week, *n* (%)	27 (15)
Less than weekly but at least once a month, *n* (%)	53 (29.4)
Less than monthly but at least once a year, *n* (%)	43 (23.9)
Less than once a year, *n* (%)	49 (27.2)
Currently experiences convulsions, *n* (%)	109 (60.2)
Has seizures while awake, *n* (%)	143 (79)
Seizure etiology	
Head trauma/brain injury, *n* (%)	28 (14.8)
Stroke/brain tumor, *n* (%)	27 (14.3)
Other causes, *n* (%)	36 (19)
Unknown, *n* (%)	98 (51.9)
Number of antiepileptic drugs (AED) currently taking	
None, *n* (%)	6 (3.3)
One AED, *n* (%)	63 (36.4)
Two AEDs, *n* (%)	65 (35.7)
More than two AEDs, *n* (%)	48 (26.4)
Side effects from current AED regimen	
None, *n* (%)	87 (47.8)
Minor inconvenience, *n* (%)	74 (40.7)
Major problem, *n* (%)	21 (11.5)
C. Psychosocial Variables	
QOLIE-10[b] scores, mean (SD)	27.1 (8.6)
BMQ-S[c] score, mean (SD)	4.8 (6)
Screening questions for health literacy	
"How often do you have someone help you read hospital materials?"	
Never, *n* (%)	31 (17.2)
Occasionally, *n* (%)	16 (8.9)
Sometimes, *n* (%)	34 (18.9)
Often, *n* (%)	28 (15.6)
Always, *n* (%)	73 (39.4)
"How confident are you of filling medical forms out by yourself?"	
Extremely, *n* (%)	23 (12.8)
Quite a bit, *n* (%)	23 (12.8)
Somewhat, *n* (%)	37 (20.6)
A little bit, *n* (%)	43 (23.9)
Not at all, *n* (%)	54 (30)
"How often do you have problems learning about you medical condition because of difficulty understanding written information?"	
Never, *n* (%)	21 (11.7)
Occasionally, *n* (%)	18 (10)
Sometimes, *n* (%)	33 (18.3)
Often, *n* (%)	43 (23.9)
Always, *n* (%)	65 (36.1)
ESS[d] score, mean (SD)	37.7 (16.1)

SD standard deviation.
[a] Missing data not included in analysis.
[b] Quality of Life in Epilepsy-10 Inventory.
[c] Beliefs About Medicines Questionnaire–Specific (Necessity minus Concerns).
[d] Epilepsy Stigma Scale.

population. Respondents had a mean age of 43 years and 31% were males. Fifty-seven percent of respondents were Caucasians while 35% were African-Americans. The majority of respondents had no more than a high school education (59.8%) and 13% had at least a Bachelor's degree. More than half had an annual household income of less than $10,000. Most respondents did not operate a motor vehicle, and more than half received disability benefits. The vast majority were not working (84.8%). As a point of reference, based on 2009–2013 data, in Jacksonville, Florida, 25.5% of persons age 25 years and older had at least a Bachelor's degree and the median household income was $47,557. 58.8% of individuals 16 years and older were employed [20].

In our study population, the mean age of seizure onset was 22 years and the average seizure duration was 21 years. More than a quarter of subjects had less than one seizure a year. The majority of subjects experienced generalized tonic–clonic seizures and seizures while awake. More than half of subjects did not have an identifiable cause for their seizures. Subjects were on a varied number of seizure medications and nearly half did not experience any medication-related side effects. The mean QOLIE-10 and BMQ-S scores were 27.1 and 4.8 respectively. Around a third of subjects appeared to experience serious issues with health literacy. The mean Epilepsy Stigma Scale score was 37.7.

Religion, acceptance, and self-distraction appeared to be the coping mechanisms utilized most often while substance abuse, denial, behavioral disengagement, and humor appeared to be employed the least (Supplementary Material 2).

On univariate analysis higher stigma scores were associated with younger age (Pearson correlation $R = -0.164$; $p = 0.03$), marital status ($p < 0.01$ ANOVA; $p = 0.03$ Bonferroni correction when comparing single and widowed status), race ($p < 0.01$ ANOVA; $p < 0.01$ Bonferroni correction when comparing Caucasians to non Caucasian non African-Americans; $p < 0.01$ Bonferroni correction when comparing African-Americans to non Caucasian non African-Americans), driving ($p < 0.01$ t-test when comparing non-drivers to drivers), work status ($p = 0.01$ ANOVA; $p = 0.03$ Bonferroni correction when comparing part-time employed to full-time employed; $p = 0.02$ Bonferroni correction when comparing unemployed to full-time employed), seizure etiology ($p < 0.01$ ANOVA; $p < 0.01$ Bonferroni correction when comparing head trauma/injury to stroke; $p < 0.01$ Bonferroni correction when comparing unknown cause to stroke; $p = 0.01$ when comparing other causes to stroke), higher (poorer) QOLIE-10 scores (Pearson correlation R 0.36; $p < 0.01$), ability to fill out medical forms by oneself ($p = 0.04$ Kruskal–Wallis), and experiencing difficulties understanding written information (<0.01 Kruskal–Wallis). When examining coping tendencies, stigma scores were also associated with use of denial (Spearman's rho = 0.15; $p = 0.04$), behavioral disengagement (Spearman's rho = 0.33; $p < 0.01$), and venting (Spearman's rho = 0.2; $p < 0.01$) (Table 2).

Gender, ethnicity, educational level, annual household income, receiving disability benefits, age at seizure onset, seizure duration, seizure frequency, experiencing convulsions, having seizures while awake, number of AEDs being currently taken, severity of adverse effects from AEDs, BMQ-S scores, and having someone help read hospital materials were not associated with stigma scores. Likewise, the use of self-distraction, active coping, substance abuse, emotional

Table 2
Association between Epilepsy Stigma Scale mean scores and significant demographic, clinical and psychosocial variables.

Variable	*p*-value	Correlation
Age	0.03[a]	−0.164
Marital status	<0.01[b]	
Race	<0.01[b]	
Driving	<0.01[b]	
Work status	0.01[b]	
Seizure etiology	<0.01[b]	
QOLIE-10[e] scores	<0.01[a]	0.36
Health literacy screening questions		
"How confident are you of filling medical forms out by yourself?"	0.04[c]	
"How often do you have problems learning about your medical condition because of difficulty understanding written information?"	0.01[c]	
Coping strategies		
Denial	0.04[d]	0.15
Behavioral disengagement	<0.01[d]	0.33
Venting	<0.01[d]	0.2

$p < 0.05$.
[a] Pearson correlation.
[b] *t*-test/ANOVA.
[c] Mann–Whitney/Kruskal–Wallis.
[d] Spearman's rho.
[e] Quality of Life in Epilepsy-10 Inventory.

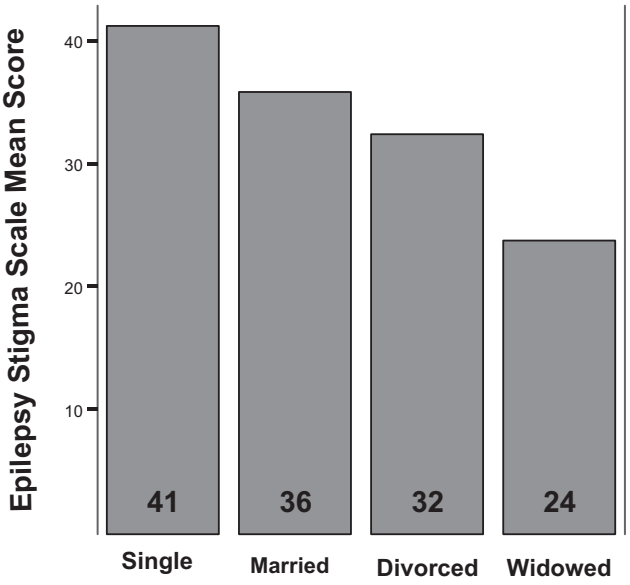

Fig. 1. Association between Epilepsy Stigma Scale mean scores and marital status. $p < 0.01$ (ANOVA). Single > widowed $p = 0.03$, Bonferroni.

support, instrumental support, positive reframing, planning, humor, acceptance, religion, and self-blame were not associated with stigma scores (see Supplementary Material 3).

Multiple linear regression (Table 3) indicate that being single (Fig. 1), higher (poorer) QOLIE-10 scores (Fig. 2), and difficulties understanding written information (Fig. 3) were independently associated with higher (poorer) scores on the ESS. The use of behavioral disengagement was also associated with poorer ESS scores (Supplementary Material 3).

5. Discussion

Our study results indicate that perceiving higher levels of felt stigma among PWE is significantly and independently associated with certain traits such as being single, having poorer quality of life, having difficulty understanding written information, and use of behavioral disengagement as a coping mechanism. These findings indicate that among PWE, the perception of societal disregard because of their medical condition is not an isolated construct by itself, but likely associated with other co-existing factors such as the lack of adequate social support, inadequate health literacy, poor quality of life, and use of maladaptive coping mechanisms.

Table 3
Multiple linear regression of variables associated with Epilepsy Stigma Scale mean scores.

Variable	B	Std. Error	Sig	95% confidence interval	
				Lower	Higher
Constant	29.9	8.4	0.00	13.34	46.49
Age	−0.1	0.09	0.26	−0.28	0.08
Marital status	−4.027	1.58	**0.01**	−7.14	−0.91
Driving	3.85	2.86	0.18	−1.81	9.5
Work status	−0.62	2.14	0.77	−4.84	3.61
Seizure etiology	0.8	0.8	0.32	−0.78	2.39
QOLIE-10[a] scores	0.45	0.15	**<0.01**	0.16	0.74
Confident of filling medical forms	0.3	1.05	0.77	−1.77	2.37
Difficulty understanding written info	−2.19	1.01	**0.03**	−4.19	−0.19
Self-distraction	0.27	0.65	0.68	−1.01	1.55
Behavioral disengagement	2	0.077	**0.01**	0.49	3.51
Venting	0.67	0.69	0.33	−0.69	2.04

Variables with $p \leq 0.05$ using univariate analysis were included in analysis and are shown in bold.
Method: Enter; $p < 0.01$.
[a] Quality of Life in Epilepsy-10.

The association between not being married and having higher levels of stigma has already been reported by other authors [16]. Although having epilepsy may occasionally be a source of family stress [21], in general, being married provides the social support vital to the well-being of an individual with epilepsy [22]. PWE with strong social support report less debilitation due to their condition and develop an increased sense of control over their lives, allowing them to possess better coping mechanisms for handling adversity [23]. Higher levels of social support among PWE are associated with such factors as being married, completing college degrees and having higher annual incomes [24]. The South Carolina Health Outcome Project on Epilepsy concluded that PWE with the highest level of social support had significantly lower reported stigma scores [25].

Our study also reveals a direct association between the severity of felt stigma and poorer scores on the QOLIE-10. The relation between increased perceived stigma and poor quality-of-life scores has also been seen in other studies [6–9,26]. Viteva [10] examined the association between a 3-item stigma scale and overall QOLIE-89 scores and its various subscales. The author found a significant relation between higher stigma scale scores and poorer overall QOLIE-89 scores as well as scores on most QOLIE-89 subscales, except for "change in health" and "sexual relations". Interestingly, using multiple linear regression, Leaffer and colleagues [27] showed that the association between self-reported stigma and quality of life was significant only in PWE of lower socioeconomic status. This finding is especially relevant to our study that also focuses on an indigent population.

Our study does not allow us to determine whether self-stigmatization is a cause of, or the consequence of poor quality of life among PWE. However, it emphasizes the importance of determining whether improving the quality of life of PWE can decrease the amount of perceived stigma. Some avenues for future

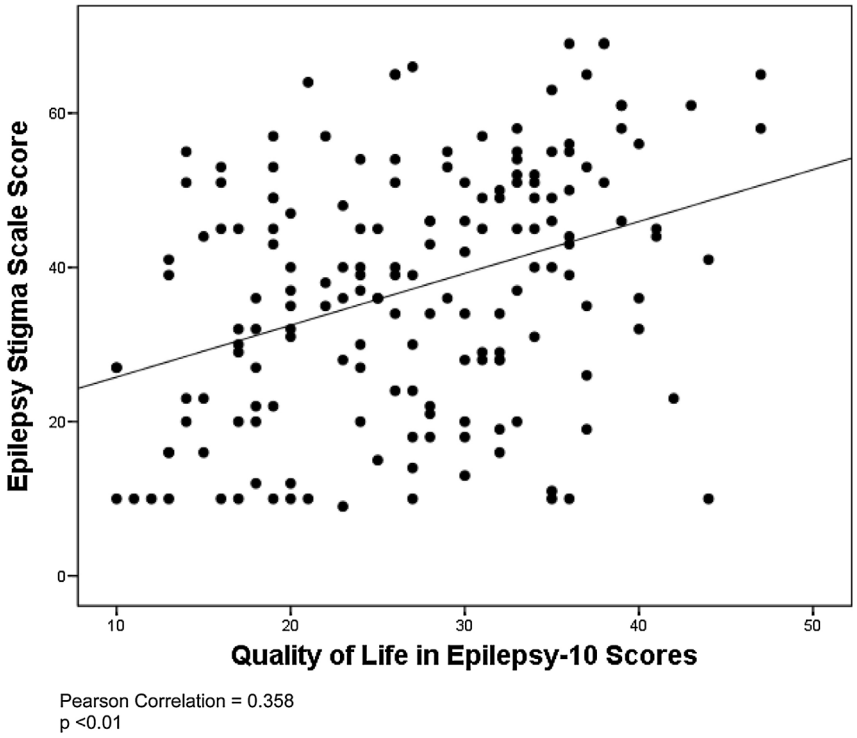

Fig. 2. Association between Epilepsy Stigma Scale and Quality of Life in Epilepsy-10 scores. Pearson correlation = 0.358, $p < 0.01$.

researches would be to determine whether enhancing the social support and/or adequately managing depressive symptoms among PWE may lead to enhanced quality of life and decreased feelings of stigmatization. An earlier study by Amir and colleagues [28] showed that there is a significant correlation between good social support and superior quality of life scores among patients with epilepsy. Similarly, Whatley and colleagues [29] studied 147 patients with epilepsy and confirmed the positive relation between social support and quality of life as well as a negative correlation between stigma and quality of life. Tracy and colleagues [30] showed that poor overall QOLIE-10 scores correlate significantly with the presence of depression. The importance of determining whether treating depression improves the quality of life of PWE cannot be understated. Though under-diagnosed, it is generally accepted that depression is much more prevalent among PWE compared with the general population [31], with Kanner and Palac [32] indicating that up to 80% of individuals with epilepsy report having feelings of depression.

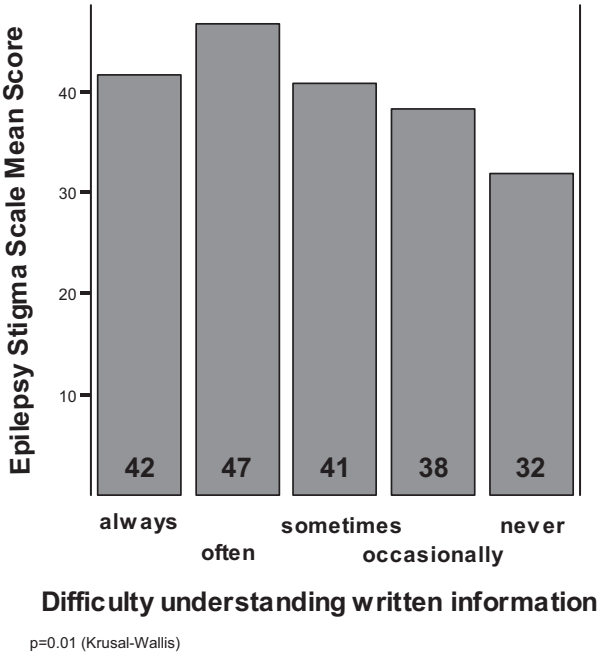

Fig. 3. Association between Epilepsy Stigma Scale mean scores and difficulty understanding written information. $p = 0.01$ (Krusal–Wallis).

To the best of our knowledge this is the first study to suggest a link between felt stigma and decreased health literacy among PWE. Previous works have examined the various interactions between stigma and health literacy. There is a shame and stigma that comes directly from having low levels of health literacy [32,34]. Easton and colleagues conducted a face-to-face interview of adults in the United Kingdom with poor health and limited health literacy to explore their perspectives on healthcare access and self-management. An important finding of their study was that limited health literacy significantly affected subjects' social engagement as well as their ability to fully utilize healthcare resources, such as conversations with the healthcare staff to cover up their lack of understanding. Many of these behaviors could be traced back to early childhood experiences of being stigmatized [33,35]. Unfortunately, even healthcare providers may unknowingly interact with low health-literate patients in a manner that heighten their own felt stigma [36].

Coping reactions have been traditionally classified as applying either engagement (approach or problem-focused) or disengagement (avoidance or emotion-focused) techniques. Engagement coping strategies are employed by individuals who attempt to actively manage their medical condition. Examples of these include active planning, positive reframing, and information seeking. On the other hand, disengagement coping strategies are typically an attempt to distance the individual from the source of stress and are utilized when the stressor is thought to be excessive or insurmountable [37].

Our study shows that disengagement coping strategies such as use of venting, behavioral disengagement, and self-distraction

were associated with increased levels of felt stigma. Of these, the use of behavioral disengagement retained significance on multivariate analysis.

Behavioral disengagement is a type of disengagement coping strategy wherein an individual intentionally decreases the amount of effort necessary to deal with a stressful situation [38]. Such strategy is typically employed when the amount of stress encountered is thought to be excessive or unsurmountable. Our study indicates that stigma is seen more often in PWE who have difficulties dealing with stress. Such coping difficulties are likely associated with the above-mentioned issues of limited social support, poor quality of life, and limited health literacy.

An important question that remains unanswered is whether a relation exists between felt and actual stigma. In many advanced societies, a significant number of discriminatory laws against PWE that were present as recent as the mid-20th century have already been rescinded [39] and public misperceptions against epilepsy is decreasing [40–42] while employer attitudes toward PWE are improving [43]. According to Scrambler and Hopkins [44], while a significant number of individuals with epilepsy experience felt stigma, only a few can recount actual experiences of discrimination. Future studies will be needed to define precisely the complex relation between perceived and actual stigma. However, the importance of felt stigma per se cannot be understated as this is what influences patient behaviors such as the non-disclosure of their disorder in social gatherings and in the workplace.

Our study has several limitations. We focused on a population of PWEs being followed at a level 4 epilepsy center in downtown Jacksonville, Florida. A significant number of our patients are indigent and have less than a high school education. The results of our study are most relevant to this patient subtype population and may not be applicable to other epilepsy groups. Also, the data collected were obtained from subjects who consented to participating in the study and were asked to self-report their information when answering the questionnaire. Thus, there is a tendency for both sampling and responder bias based on the patients' own perception of the questions and perhaps even their own personal biases. Lastly, our study focuses on PWE who consider themselves to be their own primary caregiver and are able to complete the survey on their own, limiting the generalizability of our study conclusions to this population. For many PWE who are dependent on caregivers, the perceived stigma of their caregivers likely affect the attitudes PWE develop toward their condition.

Despite these limitations, our results paint a compelling profile of a PWE who has greater perceived stigma. It takes on additional significance because our study focuses on an indigent population and indicates that there are measures that can and should be taken to decrease the amount of stigma perceived. These include heightening the level of social support for and among PWE, improving their health literacy, and enhancing their quality of life. One means of enhancing the social support would be to provide PWE as well as their family members and caregivers with adequate epilepsy education. This would help reduce the stigma associated with the condition [45] while helping appreciate the legitimate needs of PWE [46]. The use of support groups for both caregivers and PWE also provide the much-needed emotional support through their interaction with other individuals and families in similar predicaments [47]. The use of psychotherapy also has a positive influence on family members by helping them to cope better with their situation and further optimize their caregiver role [48]. In addition, it is also equally important to continually assess the readability of educational materials and websites utilized by PWE and the general public in order to ensure that they are clearly written, easy to comprehend, and culturally relevant [49–52].

In a survey of 165 adult PWEs conducted by Paschal and colleagues [53], two-thirds of respondents were of the opinion that better public education on epilepsy would significantly decrease the amount of stress and problems they experienced in their own lives. These individuals believed that the most common misunderstandings of the general public included not knowing how to react to seizures, believing that all epilepsy patients suffered severe seizures, and thinking that epilepsy is a mental illness. The use of television advertisements, information in doctor's offices, and the use of workplace programs were thought to be the most effective ways to educate other PWE as well as the general public.

Lewis and Parsons [54] surveyed/interviewed children and young adults with epilepsy in an attempt to determine the degree of stigma felt and determine ways to effectively deal with it. Study results showed that while a significant number of children and young adults with epilepsy reported feelings of stigma and shame, many of them expressed a readiness to talk about their feeling when allowed to do so sensitively. These findings have important implications for the way schools and services function to fully include children and young people with epilepsy.

Despite advances in therapy and improved societal acceptance of PWE, felt stigma remains a significant concern of those afflicted with this condition. Our study identifies those variables associated with increased felt stigma and suggest ways to lessen the impact. Measures that lessen the burden of felt stigma among PWE are necessary in order to help these individuals deal with their condition and live fuller lives.

Conflict of interest

The authors do not have any conflicts of interest to disclose.

Disclosures

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this article is consistent with those guidelines.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.seizure.2015.06.006.

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